

Policy Options for Assisting Child SSI Recipients in Transition

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Executive Summary

The transition process for a child Supplemental Security Income (SSI) recipient nearing the age of 18 can be quite complicated. From a programmatic standpoint, all child SSI recipients have their eligibility redetermined under the adult SSI disability requirements at age 18. Potentially more important, many child SSI recipients are also at the age when they must prepare for life beyond secondary school. The choices made during this important transition could have long-term implications for a child's future employment prospects, particularly given the typically long durations of participation and strong work disincentives associated with SSI participation.

The purpose of our analysis is to examine concerns related to this transition process and suggest policy options for consideration by the Social Security Administration's (SSA) Ticket Advisory Panel. Our findings are based on an extensive literature review of programs that serve child SSI recipients and semi-structured interviews with experts familiar with the problems facing youth during this transition.

In previous reports, the Ticket Advisory Panel has suggested expanding eligibility for the Ticket program to child SSI recipients age 17 to 18 as one possible mechanism for improving independent living options for this population (Ticket to Work and Work Incentives Advisory Panel 2001). We build off this initial suggestion by examining other possible mechanisms for improving independent living options for "transition age" (i.e., youth nearing age 18) child SSI recipients.

The paper first provides a general overview of the programs and policies that might influence the economic decisions of child SSI recipients including SSI, Medicaid, rehabilitation programs, and education programs. We also summarize the relevant findings from our literature review.

Our program and literature review suggest a number of potential problem areas related to the transition process of child SSI recipients. We identify several specific concerns, which include:

- Work disincentives associated with SSI and Medicaid;
- Possible conflicts between provider and individual incentives;
- Obstacles in accessing work preparation services;
- Lack of coordination of services across agencies;
- Low expectations for youth with disabilities by parents and administrators;
- Lack of access to educational opportunities; and
- Limited research information on transitions.

A summary of the policy options we identify for each of these concern areas is shown in the ***Executive Summary Table***. Because of the diversity within the child SSI population and the complexity of the transition process, there is no “one size fits all” option that would universally improve this transition for all child recipients. Rather, we identify several policy options to address these multiple concerns.

It is important to note that that this summary represents a list of *policy options* rather than a specific set of *policy recommendations*. Our ability to make specific recommendations is hampered by limitations in the literature regarding the transition process. For example, we cannot make specific recommendations on, say, expanding the scope of VR for all child SSI recipients because we do not know the potential number of recipients who could take advantage of those services. Nonetheless, the concerns and policy options identified here represent an important starting point in setting a policy agenda for this population.

In assessing specific options and concerns, it is important to balance the overall objectives of the SSI program before making decisions on specific policy directions. In some cases, the options outlined above may change the purpose of the child SSI program. For example, the temporary disability option is a fundamental departure from the SSI program, which is intended to provide permanent disability cash benefits. Alternatively, it is important to balance options that are possible within the context of the current SSI program, such as balancing the need to improve work incentives with the objectives of providing cash assistance to low-income children with serious disabilities. Indeed, if policies to reduce work incentives for this group were implemented, there could be a political backlash if a large number of SSI youth, who initially became eligible because of severe disability, started entering employment.

Because of these issues, the SSA Ticket Advisory Panel will need to make important decisions about whether specific options could be incorporated into the existing child SSI program, or if substantial rethinking of the program is necessary to improve outcomes of youth with disabilities.

The Ticket Advisory Panel should also consider these concerns and options in light of upcoming legislative initiatives. While there are no major proposed legislative changes to the SSI program on the table, important reauthorizations are on the table for WIA and IDEA. Some of the policy options proposed here, especially those that fall under our general areas of concern related to vocational/work preparation services, coordination of services, and education opportunities, could have some relevance to those reauthorization decisions. Additionally, we suggest several different types of demonstration projects that could be implemented independent of a major policy initiative to gain more information on this important area.

Executive Summary Table: Summary of Concerns and Options

Concerns	Options
Work Incentives	
The SSI program includes several disincentives that discourage work and even participation in work preparation activities for many child SSI recipients. These disincentives are likely further complicated by the age 18 redetermination decision.	<ul style="list-style-type: none"> • Expand the use of PASS and IRWEs for child SSI recipients. • Remove the earnings cap covered under the SEIE. • Exclude all child earned income in the calculation of SSI benefits.
Child SSI recipients do not have access to a temporary source of cash benefits (or other supports).	<ul style="list-style-type: none"> • Extend eligibility for benefits beyond age 18. • Create a temporary disability program for some segment of child SSI recipients.
The potential loss of Medicaid benefits is a strong work disincentive even for those with limited earnings.	<ul style="list-style-type: none"> • Provide Medicaid waivers to be consistent with SSI work incentives programs. • Transitional Medicaid assistance could be guaranteed for former child SSI recipients for some set period.
Provider Incentives	
There is a general need to improve individual incentives for self-sufficiency in non-SSA delivery programs.	<ul style="list-style-type: none"> • Tie funding for programs to individual outcomes • Develop interagency collaboration to set objectives across programs (e.g., agencies could develop joint waivers that empower consumer choice and more sharply tie incentives for providers to client outcomes within specific programs, as well as across programs).
Vocational/Work Preparation Services	
Vocational Rehabilitation is the foremost public avenue for work services for people with disabilities, but access for many youth is very limited.	<ul style="list-style-type: none"> • Make youth a priority group for VR agencies. • Expand payment options for serving child SSI recipients.
Access to other vocational preparation activities at the state level is generally limited, particularly at One-Stop Career Centers.	<ul style="list-style-type: none"> • Lower the age range for mandatory service at One-Stops to age 16. • Expand the Disability Program Navigator project.

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Coordination of Services	
There is generally no explicit facilitator, planner, or coordinator focused exclusively on the transition process and the complex mix of programs available to child SSI recipients.	<ul style="list-style-type: none">SSA could develop a role for a representative to participate in the IEP process.
Educational Opportunities	
The focus on high stakes testing and integrating students with disabilities into mainstream classrooms has created incentives for many local education agencies (LEAs) to cutback Vocational Education programs.	<ul style="list-style-type: none">SSA and DOE could develop demonstration projects and databases to better understand these issues.SSA and DOE could design options together that are consistent with broader trends in the educational system.
Low enrollment rates in post-secondary education for youth with disabilities from special education programs.	
Expectations by Parents and Administrators	
Unrealistically low expectations for a young person’s ability to work can lead to lack of work preparation and limited options.	<ul style="list-style-type: none">Parent and/or youth advocacy training can encourage parents and youths to advocate for their children or themselves.Expand options for vocational preparation for competitive work.
Research	
The lack of research information on transition outcomes of youth with disabilities in general, and child SSI recipients in particular, makes it difficult to identify specific policy directions in serving this population.	<ul style="list-style-type: none">Researchers should be able to use upcoming data sources from SSA and DOE to examine a variety of transition issues.Develop an interagency research center across key government agencies, especially SSA and DOE.

I. OVERVIEW

The transition process for a child Supplemental Security Income (SSI) recipient nearing the age of 18 can be quite complicated. From a programmatic standpoint, all child SSI recipients have their eligibility redetermined under the adult SSI disability requirements at age 18. Potentially more important, many child SSI recipients are also at the age when they must prepare for life beyond secondary school. The choices made during this important transition could have long-term implications for a child's future employment prospects, particularly given the typically long durations of participation and strong work disincentives associated with SSI participation.

The purpose of our analysis is to examine concerns related to this transition process and suggest policy options for consideration by the Social Security Administration's (SSA) Ticket Advisory Panel. In previous reports, the Ticket Advisory Panel has suggested expanding eligibility for the Ticket program to child SSI recipients age 17 to 18 as one possible mechanism for improving independent living options for this population (Ticket to Work and Work Incentives Advisory Panel 2001). We build off this initial suggestion by examining other possible mechanisms for improving independent living options for "transition age" (i.e., youth nearing age 18) child SSI recipients. Because child SSI recipients might participate in a variety of other services and programs, such as special education, Medicaid, and Vocational Rehabilitation, we also examine the influence that other programs could have on transition decisions for this population.

Our findings are based on an extensive literature review of programs that serve child SSI recipients and semi-structured interviews with experts familiar with the problems facing youth during this transition. The literature review builds off our previous work in examining transition outcomes for several different subgroups of youth with disabilities, including SSI recipients (Wittenburg and Maag, 2003; Aron, Loprest, and Steuerle, 1996). We supplement these findings by conducting semi-structured interviews with experts in the child disability area across a range of different programs and services, including researchers, government officials, disability advocates, Ticket Advisory Panel members, and other stakeholders. Our primary objective in these interviews is to identify specific concerns related to the transition process and discuss the viability of a range of policy options, including the potential advantages and limitations of each option.

We identify several policy options that could potentially enhance adult independent living opportunities for current transition age child SSI recipients. However, our ability to assess the viability of specific options is generally limited in most cases because of the lack of empirical information on current cohorts of transition age child SSI recipients. Nonetheless, these options should provide an important starting point for the Ticket Advisory Panel in addressing several concerns related to the transition process.

We begin by providing background information on the programs and services available to transition-age child SSI recipients. We supplement this background information with a summary of existing findings on transitions by child SSI recipients, as well as applicable findings on the transitional experience of other groups of youth with disabilities, including experiences from other programs and countries. Our program summary and

literature review provide important contextual information on program rules, work incentives, overlaps across programs and transitional experiences that we use to identify specific areas of concerns related to the transition process and possible policy directions. Finally, we conclude with a summary of our findings.

II. CURRENT SYSTEM

To identify initial areas of concerns related to the transition process, we review the programs and policies that might influence the economic decisions of child SSI recipients including SSI, Medicaid, rehabilitation programs, and education programs. We provide a general overview of each the major programs and highlight potential concerns related to the transition process. Of particular interest is the potential influence that these programs, particularly SSI, have on transition decisions related to work, program participation, and independent living.

A. SSI

To qualify for SSI benefits, children must meet specific income, asset, and disability criteria. The income and asset criteria are based on a complex set of deeming rules that take into account parent or guardian's income and assets, as well as any earnings by the child. To meet the disability criteria, a child must have "a medically determinable physical or mental impairment which results in marked and severe functional limitations, and which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months" (SSA, 1999).¹

Because of the complexity of the disability determination process, the SSI application process can be quite lengthy. In many cases, SSA obtains information on a child's disability status from multiple sources, including teachers, administrators, day care providers, and/or other family members who can provide independent assessments of the child's functions. In general, disability determinations can take approximately three months, though many children who are initially rejected by SSA will likely reapply for benefits using SSA's appeals process.²

Despite the long application process, there is a strong incentive for many low-income parents to apply for SSI for their child. Benefit levels are higher than most other means-tested programs for children (including Temporary Assistance for Needy Families (TANF)), there are no work requirements for the applicant or parents, and most SSI recipients are eligible for Medicaid. In 2003, the maximum federal SSI payment for a child was \$552 per month (approximately 75% of the poverty line for an individual), and many states provided a separate supplement to the federal payment, ranging from a few dollars to approximately \$150 per month. Medicaid, which is discussed in more detail below, further enhances the value of these benefits by covering important medical expenses. For example, for a child with average monthly medical expenditures of \$1,000

¹SSA also has separate eligibility and benefit criteria for applicants who meet the disability requirements for blindness. According to SSA (2003), an "individual is consider statutorily blind if his or her central visual acuity is 20/200 or less in the better eye, with the use of correcting lens."

² For example, initial determinations average approximately 120 days. While the majority of initial SSI applications are rejected, most reapply for benefits using SSA's appeals process. SSA has a multi-layered appeals process, which includes a re-examination by other Disability Determination Service (DDS) officials not involved in the claim, a review by an Administrative Law Judge (ALJ), and finally appeals to the courts.

(which is approximately the average for Medicaid participants who are classified as “disabled”), the total monthly value of the SSI and Medicaid benefit is over \$1,500.

Eligibility continues as long as the child meets SSA’s disability, income, and asset eligibility requirements. SSA periodically reevaluates these requirements, including disability status, during continuing disability reviews (CDRs). SSA conducts CDRs at least once every three years, unless the child’s health condition is not expected to improve. SSA can also conduct a CDR if they expect the child’s impairment will improve in the near future.

1. Recent Trends and Policy Changes

An important issue in improving policy options for child SSI recipients is to recognize the major changes that have transformed the program in recent years. These changes provide some insight on the potential issues that could influence future policy options.

In the early nineties, the child SSI program grew to become a major cash benefit program for youth with disabilities and their families. From 1990 through 1996, the number of child SSI recipients increased by over 250 percent, from 265 thousand to 955 thousand (SSA, 1997). This growth was attributable to a number of factors, though the largest was likely the legislative changes and legal decisions that expanded the child disability eligibility requirements in the early nineties (Stapleton, Wittenburg, Livermore, and Fishman, 2002).³

Concerns arose, however, over the rapid growth in the caseload and potential fraudulent claims. According to Auxter, et al. (1999), several media reports fueled demands for reform, including charges that children were coached to behave inappropriately to obtain benefits.⁴

Largely in response to these concerns, policy makers instituted several important reforms to restrict program access. As part of these changes, Congress eliminated individual functional assessments, which essentially tightened child disability eligibility requirements. SSA was also ordered to redetermine the cases of SSI children whose eligibility might terminate under the provisions of the legislation. While growth has been stemmed following these changes, there is still a very large population of child SSI recipients (approximately 850,000 in 2000).

³ In 1990, the famous Zebley court decision altered the child disability eligibility rules by adding a functional limitation component parallel to that of adults, thereby lowering the level of severity required for children to be eligible. Researchers have also identified other factors that have influenced growth over this period, including the economic downturn in the early nineties, changes in state welfare programs, changes in the adult SSI program (increasing joint applications from child and adults), and efforts by disability advocates (Stapleton, Wittenburg, Livermore, and Fishman, 2002). Unfortunately, the effect of individual factors on the overall caseload is not known.

⁴ A House Ways and Means Committee study, however, found little evidence of fraud despite these media reports (National Commission on Childhood Disability, 1995). Nonetheless, the heavy influence of media reports based on anecdotal evidence generally had more influence on policy makers than the research findings from that report.

The most important of these changes for transition age recipients, however, was the requirement that all 18-year-old SSI recipients undergo a medical redetermination to determine whether they meet the disability criteria under the adult standards. SSA conducts the redetermination within one year of the 18th birthday (or in the place of a CDR). The uncertainty of the redetermination outcome likely means that child SSI recipients and their families must make some important decisions in preparing for the redetermination.

The evolution of policy in recent years suggests an increased interest in moving away from the idea that the child SSI program should provide a lifetime of benefits. Given this shift in focus, it is important to develop policy options that provide child SSI recipients with more opportunities, particularly related to employment, to make a successful transition into independent living after age 18. In developing these options, however, it will be important to ensure program integrity, as reports of fraud can have a major unanticipated impact on the entire program.

2. Work Incentives

Child SSI recipients interested in gaining employment experience have some complicated choices to make because their SSI benefit amount can be reduced for any increases in child or parental income, including earnings. In general, beyond certain earned income disregards, child SSI recipients could lose \$1 for every \$2 of parental or child earnings. Unearned income, such as Disability Insurance (DI) payments, offset SSI benefits amounts dollar for dollar. After certain thresholds of earned and unearned income, a child could risk losing their SSI and Medicaid benefits.

To promote work among child SSI recipients, SSA has developed several work incentive programs. The largest of these incentives is the Student Earned Income Exclusion (SEIE). The SEIE allows a child who is regularly attending school to exclude earnings from the calculation of their SSI benefit. In 2003, a child recipient could exclude up to \$1,340 per month in earnings or up \$5,410 for the year. Two other work incentive programs, Plan for Achieving Self Support (PASS) and Impairment Related Work Expenses (IRWEs) deductions, generally allow SSI recipients to deduct certain expenses from their earnings while working in calculating the SSI benefit.⁵ A final work incentive

⁵ A PASS is a written plan, approved by SSA, that specifies an employment goal to be achieved in the future and the expenditures necessary to pursue that goal. Under IRWEs, a recipient can offset their earnings using a work related expense as long as the expense is necessary for the person to work, related to the person's disability, reasonable in cost and not reimbursable from other sources, and paid for by the person in a month in which he or she is working. There are three important differences across the PASS and IRWE provisions. First, the expenses from IRWEs are deducted from a recipient's earned income, rather than the total countable income. Consequently, the returns from IRWEs are smaller than PASS. For example, an IRWE expense of \$207.50 would reduce a recipient's SSI payment by \$153.25 (50% of \$500 earnings minus the \$85 disregard minus the \$207.50 IRWE expense). In contrast, under PASS, this expense is completely offset. Second, IRWE and PASS do not necessarily cover the same expenses. For example, Prero (1993) mentions that while regular employment transportation would be covered by PASS, it would not necessarily be covered under IRWE, unless the transportation need was related to a specific impairment. Finally, PASS participants must have an employment goal, whereas IRWE participants do not have to have a stated goal.

program, Section 1619, allows SSI recipients to retain their Medicaid coverage even if their earnings exceed a certain threshold where SSI benefits are no longer payable.⁶

Despite the existence of these programs, Hill (2002) notes that their usage by children is minimal. As an extreme illustrative example, he cites that only 3 SSI children in the entire country used a PASS in 2000.

A concern for many policy makers and child disability advocates, particularly with the implementation of the age 18 redetermination legislation, is that SSI work incentive provisions are too complicated and this complexity serves as a barrier to employment. This barrier could significantly limit a child's human capital development and, hence, lead to a lifetime of dependency on the roles. The risks of not gaining work experience are particularly high for those who are unsure about requalifying for SSI after age 18.

B. Medicaid

Most child SSI recipients are eligible for Medicaid, though the eligibility standards and linkages to Medicaid do vary across states.⁷ An important aspect of Medicaid eligibility for transition age youth is that coverage in some states may continue even after a person leaves SSI. Several states have rules to cover low-income adults whose disability might not be severe enough to meet SSI's strict adult disability definition and/or whose income and assets are just above state Medicaid eligibility cutoffs.⁸ Several states also have buy-in provisions that allow people with income above the Medicaid threshold to pay a premium to purchase coverage. These types of extended coverage might help alleviate the concerns regarding a potential loss of health coverage that a transition age youth could have upon entering the work force.

For those who are eligible, Medicaid covers a broad range of services that are important to many child SSI recipients, though states have some flexibility in providing certain services (Weiner 2003). Mandatory services include inpatient and outpatient hospital services; physician, midwife, and certified nurse practitioner services; laboratory and x-ray services; nursing home and home health care; family planning; and rural health clinics and qualified health centers. States also have the option to use waivers to cover a very wide range of additional services, including prescription drugs, clinic services, prosthetic devices, hearing aids, and dental care.

⁶ Under Section 1619 of the Social Security Act, SSI recipients who have earnings that exceed substantial gainful activity (SGA) level, which is \$780 in 2002, may still be SSI and Medicaid eligible.

⁷ In most states, SSI recipients are automatically eligible for Medicaid under Section 1634. In the remaining non-1634 states, referred to as Option 209(b), SSI recipients must satisfy state Medicaid needs tests for Medicaid eligibility, which are generally stricter than the SSI means test. Despite the stricter criteria, most child SSI recipients are likely eligible for Medicaid in the Option 209(b) states based on their family's low income and/or the severity of the child's impairment.

⁸ Examples of optional groups include individuals receiving state SSI supplement payments, individuals in institutionalized care, individuals in home and community based services, workers with disabilities who live in families with incomes below 250% of the poverty level, certain Medicare participants, some former SSA disability recipients, and "medically needy" individuals. Medically needy provisions generally cover individuals who have high medical expenses and are categorically eligible (e.g., disabled), but have incomes higher than state eligibility cutoffs.

General service delivery systems, including education and rehabilitation programs (described below), often rely on Medicaid as an important funding stream to fund specialized services. For example, special education programs often draw on Medicaid to provide specialized supports to youth with disabilities in classroom settings. According to the General Accounting Office (2000), the overlap of these programs in many states is so extensive that the boundaries across school and Medicaid services are often vague. Similarly, state Vocational Rehabilitation (VR) agencies use Medicaid to fund certain accommodations that might be important for, say, an employment placement or further rehabilitation.

Additionally, many specialized service delivery systems, especially the Mental Retardation/Developmental Disability (MR/DD) system, use optional Medicaid waivers to provide intermediate care facilities for the mentally retarded (ICF/MRs), and a wide range of nonmedical home and community-based services. Because these supports often include institutional support, their total costs are often very expensive (29.3 billion in 2000) (Braddock et al 2003). The MR/DD system is likely an important source of support for many child SSI recipients given that approximately one-third of current child SSI recipients list mental retardation as their primary impairment.

Medicaid expenditures for people with disabilities are much higher than for other enrollees. The average payment for all enrollees with disabilities (including adults and children) was \$11,770, which was significantly larger than the \$1,999 per person average for those without disabilities. Prior studies have shown high average levels of Medicaid expenditures for SSI children with disabilities, although there is a great deal of variation within this group. A 1990 study by Ellwood showed that among noninstitutionalized child SSI recipients in three states, Medicaid spending at the 95th percentile was 20 times expenditures at the median (Aron, Loprest, and Steuerle, 1996).

The viability of maintaining high Medicaid expenditures is a concern given mounting state deficits. For example, the Kaiser Family Foundation (2001) estimated that state revenue declines would create state budget shortfalls at \$69 billion nationally for FY2004. In response, nearly all states have tried to limit prescription drug spending, 37 states have cut or frozen provider payments, and half the states are reducing benefits or limiting eligibility. However, more cuts are anticipated in the future, which could disproportionately affect those with intensive health needs, including many child SSI recipients.

C. Rehabilitation and Training Programs

Child SSI recipients are potentially eligible for rehabilitation services from state VR agencies based on their disability status. However, to receive more intensive VR services, a child must show an ability to achieve an employment outcome. In some cases, the availability of these services could be limited because of a long waiting list, particularly for specialized services, in many states.

Those who become eligible for services work with a VR counselor to select a vocational goal and develop a plan of services with the intent to enable the consumer to achieve that

goal. To support this planning process, participants may undergo further assessments (e.g., vocational evaluation to help the consumer select a vocational goal and a plan of services) to clarify service needs. Participants then clarify their service needs in an Individualized Plan for Employment (IPE). Participants might receive a variety of services, which will likely vary depending on their characteristics, disability type, and employment needs (Hayward and Schmidt-Davis, 2000). The available statistics on young adult (age 16 to 24) VR participants suggest that many transition-age participants received services related to counseling, guidance, and job placement.

SSA has a special program that reimburses state agencies for successful employment outcomes of SSI (and Disability Insurance) recipients, which results in a decrease in SSA benefit payments. Once a recipient achieves an employment outcome, SSA reimburses state VR agencies for the actual costs of providing direct services.

While all child SSI recipients are eligible for services, only a relatively small portion of child recipients uses these services. According to Berry, et al. (2000), approximately 32,000 SSI recipients age 16 to 24 received services, of whom approximately 13,000 achieved an employment outcome.

Daniels (2003) noted that state VR funding priorities can have a major impact on the types of services provided by agencies. As an example, she noted that placing emphasis on drug addiction in the District of Columbia created incentives for VR administrators to serve more people with drug addiction, relative to other VR applicants.

Wehman (2003) also noted that the funding structure of VR limits participation by youth earlier on in the transition process. Most VR agencies view children as already having an entitlement through special education and, hence, administrators generally do not view children as a priority group. Further, because state VR agencies are generally not reimbursed until an employment outcome is achieved, these agencies are reluctant to provide employment services to youth prior to their completion of secondary school. Consequently, many, if not most, state VR agencies follow a policy of not providing rehabilitation placement services until the student is within 6 months of graduation.

Some transition age SSI recipients might obtain training and employment supports through other work programs. The largest of these programs are funded through state Workforce Investment Systems, organized under the Workforce Investment Act of 1998 (WIA) and funded in part by the U.S. Department of Labor.⁹ WIA required states to provide integrated services through One-Stop Career Centers. These centers must provide universal access to adults ages 18 and older for “core” services such as job search and placement, job vacancy listings, and initial skill and needs assessments. VR is a

⁹ The Projects with Industry Program (PWI) also creates partnerships among business, industry, labor, and the rehabilitation community to assist in providing employment opportunities for people with disabilities, though the scope of PWI is much smaller than VR or WIA. In many cases, the WIA and PWI programs coordinate service delivery through state VR agencies. Independent Living Programs also provide grants to states and nonprofit organizations to establish and support centers for independent living, which provide a number of employment-related services, including skills training.

mandatory partner in the One-Stop Career Centers under WIA. Youth under age 18 are not automatically eligible to use One-Stop Centers.

WIA also provides funds to states to serve low-income young people ages 14 to 21 with barriers to work, including youth with disabilities (Storen and Dixon 1998). These funds are generally used for employment preparation, assessments, education, supportive services, and youth development. These programs focus on activities that strengthen linkages between academic and occupational learning and other youth development activities. (Silverstein 2000). While service can take place in a variety of settings, a minimum of 30 percent of youth-targeted funds must be spent on those no longer in school (e.g. dropouts and graduates under age 21). Under the Bush administration proposal for WIA reauthorization in fall of 2003, the main focus of youth funds would be on programs for out-of-school youth.

Although states are required to serve low-income youth with disabilities under WIA, anecdotal evidence suggests “invisible walls” remain that restrict access to and prevent coordination of services for youth (Wehman 2002). Unfortunately, statistics on participation in these services are not available because of data limitations (Techico 2003).

1. *Ticket to Work Program*

In an effort to expand the availability of rehabilitation services to working age (age 18 to 64) adults, Congress enacted the Ticket to Work program in 1999. Under the Ticket program, SSA is providing SSI (and Disability Insurance) recipients with a “ticket” to purchase rehabilitation from state VR agencies and other potential providers in “Employment Networks (ENs).” The goal of this program is to expand opportunities for coordinating employment and rehabilitation for SSA disability recipients, as well as to expand the number of providers who can provide these services. Several states are currently rolling out the Ticket program and all states will implement the program over the next couple of years.

While the current Ticket program does not cover child SSI recipients, the Ticket to Work and Work Incentives Advisory Panel recently recommended that the Ticket program be expanded to child SSI recipients aged 16 and 17 (Ticket to Work and Work Incentives Advisory Panel, 2001). The Panel noted that the Ticket program could increase options for work preparation services, especially for poor and minority students that would result in eventual increases in work and decreased dependency on benefits. The Panel also recommended that young people receiving SSI and participating in Ticket under a lowered age-eligibility criteria should be protected against having a medical redetermination until they have had a chance to participate in the Ticket program.

Despite this recommendation, the Panel noted some limitations that could complicate the expansion of Ticket to transition age youth. A major concern was that the implementation of Ticket for youth could create an impression of SSA favoring early employment over other goals, such as education. Similarly, the Panel raised concerns that eligibility for this group would potentially allow states to substitute Ticket for their

obligation to provide special education services. Finally, some practical concerns were raised regarding the feasibility of expanding Ticket based on the structure of the SSI program. For example, some youth participating in Ticket could lose their benefit status after their benefit redetermination at age 18. Consequently, it could be difficult to define payment rules and outcomes for ENs for this population because a significant portion might no longer be SSI recipients after age 18.

D. Education

The school system provides a large number of services and supports to many child SSI recipients who are in school, including a centralized institutional structure that students can turn to during their secondary school years. Over the past twenty years, there has been a major movement in education policy to integrate more students with disabilities into mainstream classrooms. This movement coincided with other broader disability movements, including the Americans with Disabilities Act (ADA), which aim to integrate people with disabilities into the mainstream of society. In the course of this movement, youth with disabilities have also struggled to remove stigmatizing labels such as “normal” classrooms, which attempt to separate those with disabilities from the mainstream.

1. Special Education Programs

Youth with disabilities can receive special education services through their school, which are funded in part through the Individuals with Disabilities Education Act (IDEA). Under IDEA, states must provide free and appropriate education to all students with disabilities. Children can use services as a mechanism for integrating themselves into regular classrooms, or for obtaining specialized education or rehabilitative services (e.g., speech therapy) to supplement (or replace) their regular class schedule. States must identify, locate, and evaluate all children with disabilities who need special education and related services.¹⁰

Unfortunately, information on the overlap between SSI and special education is very limited. Presumably, most child SSI recipients could qualify for special education services based on the disability eligibility requirements. However, some recipients might not receive these services because they have dropped out of school. Alternatively, some children and their families might not have requested specialized services from their school system for various reasons (e.g., stigma, unaware of services).

Children who are eligible under IDEA receive an Individual Education Program (IEP), which formally establishes a service management framework. The IEP outlines the special education and related services (e.g., clinical and therapeutic services) that school

¹⁰ Most of these efforts are coordinated through “Child Find” activities. Parents can also call the “Child Find” system and ask that their child be evaluated. Alternatively, a school professional might ask that the child be evaluated for a disability after getting the consent of a parent. Once identified as potentially eligible for IDEA services, the child undergoes an evaluation. These evaluations are reviewed by a group of qualified professionals and parents. Both parents and professionals make the eventual eligibility decision, though parents may ask for a hearing to challenge the eligibility decision.

districts will provide the child. A team of stakeholders, which generally includes teachers, parents, school administrators, related services personnel, and students (when appropriate), work together to develop the IEP. The IEP is tailored to meet the specific needs of each individual child and allows the youth to access appropriate services while they are in school. It can include services from other programs outside the auspices of DOE that provide funding for related services, such as health care accommodations (e.g., hearing aides) (Ordovery et al. 1999). The IEP can also assist in coordinating services outside of the school setting. For example, supported employment activities can be coordinated with other school activities under the IEP.

For transition-age youth, a key component of the IEP is transition planning, which outlines roles by age 16 (sometimes 14) for participants and provides a coordinated set of activities supporting the child's movement to adult living, learning, and employment. In theory, the transition component of the IEP should assist a transition age youth in making a smoother transition from school by outlining the necessary services and supports necessary for the transition from secondary school.

While the school system provides child SSI recipients who stay in school a formal system of supports, the availability and types of supports provided through this system varies and may not be sufficient for some children. These differences could influence the expectations that parents and administrators have for many children. For example, students in poorer school districts may have fewer options for obtaining services and hence influence the child's expectations for independent living and employment beyond age 18.

One specific concern for child SSI recipients receiving services under an IEP is that IEP team members may not fully understand all of the implications associated with a child's participation in SSI, particularly during the transition stage. The role for SSA in providing transition planning assistance in the IEP process is likely limited given the relatively minimal overlap between the school system and SSA. For example, while it is likely that an IEP will account for a child's participation in SSI, SSA does not necessarily have a formal arrangement with schools in all states for a representative to advise and/or promote special work incentive programs (e.g., SEIE, PASS).

2. General Education Policy

For youth who are enrolled in primarily mainstream classrooms, which includes a majority of special education students, the recent movement towards high stakes standardized testing and setting accountability standards in public schools will likely influence many children with disabilities. Many schools now have their funding tied to performance criteria, such as grades on standardized test scores. Because of this movement, teachers and administrators are under more pressure to ensure that students have enough basic skills to pass these standardized tests, including youth with disabilities.

Some of our key informants raised concerns about the potential negative impact of high-stakes standardized testing on youth with disabilities, particularly those with mental

impairments (Berry 2003; Hallorhan 2003). One specific concern is that students with disabilities are disproportionately likely to be in danger of not passing these tests and being left behind or, worse, dropping out of school all together. These youth may have very limited options in making transition decisions and potentially even fall into the juvenile justice system.

A related concern is that the movement towards standardized testing has lead to a decrease in school resources for specialized courses, such as vocational education and training, as administrators are increasingly focused on providing students with only those skills necessary to pass the standardized tests (Boaler 2003; Cala 2003). For many youth with disabilities, particularly those who do not plan to enter post-secondary education, a cut back in vocational education could limit opportunities for further human capital development in a specialized area.

III. RECENT FINDINGS ON OUTCOMES OF TRANSITION AGE STUDENTS

We now turn our attention to the previous literature on the transition from school by youth with disabilities. While we focus on studies that examine the characteristics and outcomes of transition-age child SSI recipients, we also review relevant findings from the literature on other populations of youth with disabilities.

A. SSI

The majority of the empirical information on child SSI recipients comes from SSA administrative data. Summary descriptive statistics from these data suggests that transition age youth comprise a significant portion of all child SSI recipients. According to SSA (2002), approximately 20% (170,000) of child SSI recipients were above age 15 in 2000. The available statistics on child SSI recipients ages 13 to 17 show that this population includes a disproportionate number of children who are male (about two-thirds). Mental disorder is the primary impairment for almost 80 percent of this group, and three out of five recipients report that their primary disorder is mental retardation (SSA 2002).

Not surprisingly given the characteristics of the caseload, limited usage of work incentive programs, and the fear of a potential loss of benefits from working, relatively few child SSI recipients report any earned income. In 2000, approximately 2 percent of the child SSI recipients age 15 to 18 (3,500 recipients) reported any earnings during the year.

SSA (2001) found that approximately one-third of a recent cohort of transition-age child SSI recipients eventually lost their benefits after age 18 (including appeals) because they did not reapply for benefits or did not meet the adult disability criteria. These findings suggest that a relatively large portion of child SSI recipients must turn to alternative sources of support after age 18, including employment.

Recent findings from a SSA demonstration projects for SSI children, such as the Youth Continuing Disability Review Project (YCDR) conducted by Maximus in Maryland and Florida, provide some additional insights on the transition process. This initiative involved SSI youth in Maryland and Florida ages 15 and 16 who have had a CDR. The project was designed to assist youth in obtaining the information and services they need to successfully transition to work. Youth were given enhanced opportunity to gain information on skill assessments, career aspirations, educational goals, health care needs, reasonable accommodations, employment supports, and community and governmental transition services. The demonstration provided individual assessments, informed and motivated young people and their families about employment development opportunities, and provided linkages to services.

The findings from the Maximus study emphasized the importance of early intervention strategies, and the need for staff working with these children to develop individualized strategies to help them succeed in the workplace (Maximus, 2002). They noted a major issue in providing services is overcoming difficulties associated with the lack of coordinated services across key stakeholders in the school system who were unaware of

many special SSA program rules. To account for this issue, they advocated taking a more holistic approach that included “locating providers that will help (children) to obtain needed employability services, setting realistic education and vocation goals, generating collaborative relationships with other state and local agencies....and identifying employers that are in need of participant skills and abilities” (pp.73).

The need for these services is particularly important given some of the study’s other findings that many of these transition age youth were falling through the cracks and already had a record with the juvenile justice system (16.5 percent reported a previous arrest). These high rates of criminal records are consistent with findings from previous literature that suggest as many as 80 percent of youthful offenders have a diagnosable mental health disorder (and many have an accompanying substance abuse problem) (Maximus, 2002).

Unfortunately, the findings from the SSA administrative data and the aforementioned demonstration provide only a limited perspective on the transition process of child SSI recipients. While administrative data provide some insights on the characteristics and program transitions of child SSI recipients, they do not include information on their participation in other programs, such as special education, or in other activities, such as employment. Further, because SSA administrative data are protected by confidentiality restrictions, their use by outside researchers has generally been very limited to special SSA projects. The ability for researchers to draw on public surveys for this type of information is very limited because these surveys generally include inadequate questions on SSI receipt and small sample sizes (Wittenburg and Maag, forthcoming). The YCDR demonstration project provides some insights on the potential barriers facing youth during this process, but, because it is small in scope (e.g., only 133 project participants were included in the Maryland demonstration), it is not clear whether the findings are representative of the entire caseload.

Because of these limitations, researchers and policy makers do not have important information on several aspects of the transition process that are relevant to the development of policy options. As one researcher noted, “it’s almost like working with a blank slate” in reference to the current state of knowledge on transition outcomes of child SSI recipients (Daniels 2003). This limitation represents a major obstacle in assessing the viability of various policy options.

The good news is that the upcoming National Survey of Children and Families (NSCF), funded by SSA and scheduled for release in August 2003, should provide extensive information on the characteristics of SSI recipients. The NSCF includes a sample of approximately 12,000 current SSI recipients, former SSI recipients, and families who applied for but never received SSI. It collects information on experiences, characteristics, and needs of children with disabilities and their families that are unavailable in any other data source. It also includes an oversample of transition age students to examine some of the effects of the welfare reform legislation.

Researchers should be able to use these data to address several important questions related to the transition process, including tracking employment outcomes, continued SSI

participation, and other aspects of independent living of former child SSI recipients who are no longer recipients after age 18. Alternatively, researchers could use these data to better understand the effect that non-SSI programs have on the transitions decisions of recipients, including the overlap of SSI with special education and VR.

In addition, SSA is in the process of developing new youth demonstration projects in six states that should provide another source of valuable information on the transition experiences. These five-year demonstration projects, expected to be awarded in September 2003, will provide additional insight into issues for helping the transition of SSI youth (Mazurski 2003).

B. Findings from the General Literature

The most extensive information on transition outcomes of youth with disabilities comes from the special education literature. While the extent of the overlap between SSI and special education is not known, some lessons from this literature could be helpful in informing policy options, particularly those that relate to education programs.

Wittenburg and Maag (2002) recently compiled a comprehensive review of literature on the relationship between activities during secondary school years and outcomes three to five years later. The papers summarized in this review cover a range of outcomes, including post-secondary education, employment, compensation, independent living, and a variety of index measures that capture economic independence and/or post-school success.

Not surprisingly, the studies in their review indicated that youth with disabilities have worse post-secondary outcomes three to five years following school than those without disabilities. For example, general enrollment rates in post-secondary schools were, much higher for youth without disabilities (68 percent vs. 27 percent) (Blackorby and Wagner, 1996).

A number of factors influence post-school outcomes, though prior studies cannot disentangle the relative importance of specific factors. Specific factors that were correlated with post-secondary enrollment and employment outcomes three to five years later included individual characteristics (impairment age, race, gender); family characteristics (family income, number of parents, number of persons in household); education/rehabilitation characteristics (vocational education/rehabilitation participation, educational attainment, transition planning, satisfaction with school, test scores); work characteristics (experience, type of job); and other factors (existence of social network, community characteristics).

These findings have important implications for future research and policy directions. The fact that employment three to five years out of school is positively correlated with vocational education enrollment during secondary school years is important given current trends in schools toward cutting back vocational education funding. It's possible that these cutbacks could have important effects on future transition decisions. It is also important to account for the heterogeneity within the population of youth with disabilities

in examining outcomes. For example, employment rates three to five years after the initial school interview ranged from a low of 9 percent for students with multiple impairments to a high of 75 percent for students with a learning impairment (Wagner, Blackorby, Cameto and Newman 1993). A child's decision will likely be heavily influenced by his/her individual characteristics (especially impairment), as well as by school and family characteristics. Consequently, a "one-size fits all" approach to policy intervention is problematic given the diversity of characteristics and needs of the child SSI population.

Findings from the international community on programs that support the transition from school to work for all children and for children with disabilities in particular also provide some insights that might be relevant to the development of policy options. Several OECD countries—including Germany, Austria, Denmark, Luxembourg, and Switzerland—have a formalized vocational preparatory system using both employer-based apprenticeship and school-based vocational education. In these countries "the majority of young people focus on the attainment of occupational credentials; only a minority emphasize educational degrees as the primary vehicle for entering careers" (Lerman 2000). Because of this strong focus on formalized vocational training, the transitional experiences of youth in other countries, including youth with and without disabilities, is different from those in the United States. The experiences from a more vocational centered education system might provide some insights on policy options geared towards specialized training of youth with disabilities in the United States. For example, if youth with disabilities fared consistently better in these systems, or, in specific vocations, the lessons from these systems could point to policy options that focused on funding special vocational education programs.

A common issue in international school systems is that young people with disabilities are often segregated into separate classrooms or special schools. While many European countries, like the United States, are in the process of addressing these issues and moving toward greater inclusion, most have a history of separate education of students with disabilities. Inclusion is particularly difficult in secondary schools at the point that students opt for or are selected for specialization (e.g. general education, vocational education, or pre-university education) (OECD 1995). This finding suggests that special education students may not be included in these countries "mainstream" vocational systems. In addition, the OECD systems must be considered in the context of the relatively high rates of youth unemployment compared to the United States. Even with declines in youth unemployment in some OECD countries in the last decade, far higher rates limit the opportunities of youth. Young people with disabilities may be less attractive (for actual or employer-perceived reasons) as candidates for costly apprenticeship or other employer-connected programs.

As in the United States, there is enormous regional/local variation within most countries in special education students' access to vocational services and the existence of special projects addressing employment preparation for students with disabilities.¹¹ An OECD

¹¹ Gerry's (1998) study of the work development system for youth in Genoa, Italy is one example.

project studying the transition from school to work of youth with disabilities in OECD countries provides a number of case studies of country-specific projects (OECD 1991).

In general, many of the issues facing OECD countries in transition for young people with disabilities are similar to the United States despite the different emphasis on vocational training across these countries. A final conference of participants in the OECD study concluded that the major factors necessary for successful transition include continuity of support, coordination across involved agencies/organizations, and effective case management (OECD 1991). One successful model cited for promoting positive transition outcomes is the Kurator model in Denmark. This model included a dedicated professional in the school system that is in charge of the transition process for young special education students. Interestingly, this model seems to have some common elements with the “holistic approach” to providing transition services suggested above by Maximus for the SSA YCDR demonstration.

However, one major difference that likely does influence transition decisions is that the availability of public benefits for youth that are not affected by work participation in many OECD countries (Aron, Loprest, and Steuerle 1996). In fact, many countries have income maintenance provisions for families of children with disabilities regardless of family income. In addition, most of these countries have universal access to health care. These factors limit the disincentives to work for youth, thus simplifying the transition process.

IV. CONCERNS/OPTIONS

In summarizing the programs and previous literature related to transitions by youth with disabilities, we identified a number of concerns related to:

- Work Incentives;
- Provider Incentives;
- Access to Vocational/Work Preparation Services;
- Coordination of Services;
- Expectations for Youth with Disabilities by Parents and Administrators;
- Educational Opportunities; and
- Existing State of Research Knowledge;

Below, we summarize the major concerns under each of these categories and outline some possible policy directions that could improve independent living outcomes for child SSI recipients as they transition into adulthood.

It is important to note that our discussion focuses on policy options rather than specific recommendations. Our ability to make specific recommendations is hampered by limitations in the literature regarding the transition process. For example, we cannot make specific recommendations on, say, expanding the scope of VR for all child SSI recipients because we do not have enough information on the potential number of recipients who could take advantage of those services. Nonetheless, we do suggest options for each of the specific concerns raised either in the previous literature or during our phone calls, and identify possible avenues for addressing these concerns. We then qualify these options with the additional information that would be necessary to better understand the scope of the concern and/or implementation of a specific policy options.

A. Work Incentives

The SSI program includes several disincentives that discourage work and even participation in work preparation activities for many child SSI recipients. Child SSI recipients who are interested in working face the prospects of losing their SSI benefit, as well as Medicaid coverage, if earnings exceed a certain threshold.

These disincentives are likely further complicated by the age 18 redetermination decision. The looming redetermination decision could be a further disincentive to work for some child SSI recipients who fear that work experience might negatively influence their chances for meeting the adult eligibility criteria for SSI after age 18. Alternatively, other child SSI recipients might more actively participate in work preparation activities in anticipation of working after age 18 because of potential loss of benefits.

Expanding options to work for youth could have lasting effects on their employment opportunities as adults. Previous findings suggest that youth who have more employment

experience during their schooling years are more likely to be employed three to five years following school than those who have no work experience (Wittenburg and Maag, 2002). By gaining early access to employment, youth can gain valuable experience that will enhance their human capital, and hence improve their long-term prospects for independent living. This development is particularly important for transition age child SSI recipients who are facing the potential for a lifetime of program participation if their employment opportunities at a young age are limited. Further, the opportunities to obtain further education, training, and employment skills are much larger while a youth is in school in comparison to the opportunities this same person might have later as an adult SSI recipient.

These options would be particularly important for child SSI recipients at or near working age (i.e., above age 15). As noted above, in 2002, approximately 170,000 child SSI recipients were between ages 15 to 17. While a significant portion of this population might not be able to work because of their impairment, the findings from SSA (2001) suggests that approximately one-third of this cohort might no longer participate in SSI after the age 18 redetermination decision (approximately 57,000 recipients). Presumably, some portion of these recipients could benefit from further human capital development through early employment experiences. Further, even those children who stay on benefits after age 18 might change their decision regarding SSI participation if they had more access to employment opportunities during transition age. If successful, long-term outcomes of transition age child SSI recipients might improve to such an extent that they permanently leave the rolls, which would lead to an increase in overall national productivity and a reduction in long-term SSI payments. For example, the costs of SSA not offsetting \$1 of benefits for \$2 of earnings in terms of higher child SSI payments might be offset if a child obtains valuable work skills that leads to a short-term reliance on benefits.

Several possible policy options could improve work incentives for transition age recipients. One option would be to expand the use of current SSA work incentives, such as PASS and IRWEs, through local outreach efforts. SSA recently considered expanding the use of PASS in a potential demonstration as a means for supporting job retention for adult SSI recipients (Wittenburg, et al. 2002).¹² The advantage of this option is that it is relatively straightforward and can be implemented within the current system. However, even an expansion of work incentives through these programs might not be enough to overcome the current concerns regarding work by many child SSI recipients and their families, particularly given that the structure of IRWE and PASS provisions are complicated.

Another option that could address some of the confusion regarding the current work incentives is to remove the earnings cap covered under the SEIE. This option would allow child SSI recipients who are still in school to work at any level without penalty of losing benefits. It is important to note, however, at certain levels of income the child could jeopardize his or her Medicaid eligibility status. Consequently, even an expansion

¹² The Urban Institute and its subcontractor Westat recently submitted a design for a proposed SSA demonstration to use PASS as a means for supporting a randomized evaluation. SSA has yet to make a decision on whether to implement the demonstration.

of SEIE may not fully alleviate concerns regarding the potential loss of benefits due to increased earnings. Further, this expansion of the SEIE would not cover child SSI recipients who are not currently in school.

A more ambitious option would be to simply not count any earnings in the calculation of SSI benefits by eliminating the \$1 benefit reduction for every \$2 of child earned income (Daniels 2003). The advantage of this option is that it would increase the value of working (by removing the benefit penalty). Potentially more importantly, this option would simplify the complex work rules for child SSI recipients. Presumably, SSA benefit and planning offices and other child disability advocates could more easily present the benefits of working while receiving benefits under this option.

A related concern is that child SSI recipients do not have access to a temporary source of cash benefits (or other supports). At age 18, child SSI recipients are faced with the prospect of making what is likely a permanent decision on whether to continue participation in SSI or enter the labor market.

Some have argued that youth are not in a position to make these important decisions at age 18 because they are still in the formative stages of human capital and personal development. In many cases, these youth might not be ready to enter steady employment because they either have not finished school or have very limited work skills. Further, from a neurological perspective, children's minds are still in formative development stages even after age 18 (Wehman 2003). Consequently, many of these youth might not be at a stage developmentally where they can make an adult decision regarding employment and program participation. Finally, from a program perspective, there are inconsistencies in the age definition for youth, as child SSI benefits expire at age 18, while coverage for other programs, such as IDEA, continue through to age 22.

One option for addressing this concern is to extend eligibility for benefits beyond age 18. For example, some suggest making child benefits available through to age 22 to be consistent with the IDEA legislation. The advantage of this option is that it would bring some consistency across government programs in age definitions. Others have suggested pushing the age to 25, which would allow a youth to gain some practical workforce experience, as well as additional training and education, before making an adult decision.

Another option is to create a temporary disability program for some segment of child SSI recipients to smooth the transition process. Because the population of child SSI recipients is heterogeneous, some of our informants argued that developing separate, temporary tracks for some recipients, possibly voluntary, could improve long-term outcomes (Beckett, Gracechild, Westrom 2003). For example, some child SSI recipients could be offered time-limited benefits to age 22 or 25, while they continue to finish their schooling or transition into employment. During this period, temporary program participants could receive support while gaining valuable work force experience or other schooling that would enhance their prospects for independent living as an adult. In return, recipients would agree to leave SSI at age 22 or 25, either for good or for a certain period of time. This type of option could create a smoother transition process for many child SSI recipients, who currently face a difficult choice of leaving benefits at age 18 or

potentially spending a lifetime on SSI benefits as an adult. However, it might be difficult to determine who would be eligible for temporary benefits.

Another related concern is that the potential loss of Medicaid benefits is a strong work disincentive even for those with limited earnings. The combination of SSI and Medicaid significantly increases the value of participating in SSI for many children. However, the work rules for SSI and Medicaid are very complex and are likely confusing to some transition age youth and their families. Because of the potential uncertainty of losing benefits at age 18, some children may choose not work at all. Even those who are interested in leaving SSI completely would need to find a job to offset the combined value of SSI and Medicaid benefits, which as noted above could be over \$1,500 a month (or that offers employer health insurance) to remain economically as well off as they are on the program.

Because of the overlap between SSI and Medicaid, any option to expand work incentives or eligibility age noted above should also include options that tie in Medicaid. The Ticket to Work and Work Incentive Improvement Act (TWWIIA) recognized the importance of these ties and included options for states to expand Medicaid coverage to former SSA disability recipients who left the rolls.¹³ Presumably, states could develop waivers that could compliment the initiatives mentioned above.

Options to expand Medicaid regardless of SSI work incentive options could also potentially improve work incentives. For example, transitional Medicaid assistance could be guaranteed for former child SSI recipients for up to, say, five years. Several states have adopted this model in providing Medicaid assistance to former welfare recipients. However, the effects of this type of expansion would likely be very limited given that it would not necessarily reduce the high implicit marginal tax rates on SSI benefits (\$1 in benefit loss for every \$2 in earnings).

To assess the practicality of any of the aforementioned options, more research is needed on the human capital development of child SSI recipients, including the effects of the current program on long-term decisions related to schooling, training, employment, and program participation. For example, understanding the possible long-term employment outcomes for SSI recipients who received additional training from age 18 to 22 would provide insights on the potential for adjusting the redetermination age for adult benefits.

¹³ For example, Section 201 of the Act allows states the option to liberalize income, asset, and resource limitations for workers with disabilities who buy into Medicaid. States can also continue to offer the Medicaid Buy-in to workers with disabilities, even if they are no longer eligible for DI or SSI because of medical improvement; Section 202 of the Act extends the Medicare Extended Period of Eligibility (EPE) from four to eight-and-a-half years; Section 203 of the Act establishes Medicaid Infrastructure Grants, intended to provide assistance to states in the development of Medicaid Buy-in programs. To qualify for such grants, states must offer, or be in the process of establishing, personal assistance services capable of supporting full-time competitive employment; and Section 204 of the t Act provides funds to states to conduct Demonstrations to Maintain Independence and Employment (DMIE). These grants are intended to allow states to experiment with programs to provide Medicaid coverage to workers with significant impairments that, without medical assistance, will result in disability (Wehman, et al. 2002).

One potential mechanism for obtaining this information could be to develop a small-scale demonstration program around one of the options mentioned above.

B. Provider Incentives

There is a general need to improve individual incentives for self-sufficiency in non-SSA delivery programs. Some Ticket Advisory Panel members expressed concern that a significant portion of non-SSI disability-related expenditures goes directly to large service delivery systems or providers whose incentives may not be aligned with individual SSI recipients (Beckett, Gracechild, Westrom 2003). For example, some provider organizations who provide employment support services to child SSI recipient are not necessarily familiar with all of the program work incentives options, such as PASS and IRWEs. Hill (2002) notes that a major problem that exists in promoting these work incentives is that the service provider system, outside SSA, is neither expected to nor rewarded for focusing on empowering individuals to self-support and to achieve financial and social health. Currently, administrators across programs do not have incentives for providing early intervention services even though a youth might significantly benefit from these services.

Wehman et al (2002) noted that the issue of providing proper funding incentives for large providers is particularly important in the area of supported employment. They noted that while the wages for those in supported employment clearly exceed the wages of individuals with similar disability labels still in segregated employment, a great deal of funding and policy continued to support segregation over integration in day services and employment. For example, for every one person with a disability working in integrated settings through supported employment, 4.5 people remain in segregated settings. While they were optimistic that more MR/DD agencies were now moving towards integration, their findings underscored the need for examining provider incentives in promoting outcomes for people with disabilities.

The most straightforward mechanism of improving these incentives is to tie funding for programs to individual outcomes. Not coincidentally, a major goal for the Ticket program is to expand consumer choice options, in part as a response to the lack of consumer options within the service delivery system for adults. In the last ten to fifteen years, policy and funding changes have led to increases in integrated employment for people with disabilities. Similarly, state VR agencies no longer accept segregated work as an employment outcome and several Medicaid waivers tie funds directly to integrated employment options.

Before structuring these incentives, there is a need for interagency collaboration to set objectives across programs. The need for this collaboration in improving incentives for child SSI recipients is especially strong across the Administration on Developmental Disabilities (under the Department of Health and Human Services), Department of Education (DOE), Centers for Medicaid and Medicare Services, and SSA. It is important to define a uniform set of outcomes across programs that administrators can collaboratively work toward improvement. These agencies could decide to emphasize an array of activities, including employment, schooling and other training. The key,

however, will be in choosing incentives that are in the best interests of the client and consistent across programs.

One option is that agencies could develop joint waivers that empower consumer choice and more sharply tie incentives for providers to client outcomes within specific programs, as well as across programs. For example, local school districts and developmental disabilities agencies could jointly fund job placement and on-going support services for students with significant disabilities who may already be receiving SSI benefits (Wehman 2002).

A related alternative is to develop demonstration projects through SSA or CMS that fund initiatives that promote independent living outcomes of youth with disabilities. The YCDR demonstration program recently funded by SSA is an example of one such program. Presumably, SSA could fund other types of demonstrations in collaboration with CMS and DOE.

An obstacle in implementing these options, however, is overcoming short-term political horizons that may overshadow longer-term objectives. Specifically, because the outcomes of child SSI recipients will not necessarily be realized for several years, the benefits of implementing such policies, which could include significant upfront investments, could be limited for policy makers seeking more short-term impacts. Further, the objectives of different agency officials could conflict, thereby complicating agreements for interagency collaboration.

C. Vocational/Work Preparation Services

Vocational Rehabilitation is the foremost public avenue for work services for people with disabilities, but access for many youth is very limited. Many VR agency officials currently view the school system as the major area of support for youth under the age of 18. Consequently, as noted earlier, most VR agencies follow a policy of not providing service to any youth until the student is within six months of graduation.

One policy option to expand VR services for child SSI recipients would be to make children a priority group for VR agencies. This option is similar to those mentioned above under provider incentives in that it ties funding to a specific priority group, thereby aligning the incentives of administrators more closely with those of the individual. For example, special waivers that provide direct funding for VR agencies to work with schools could make the system more responsive to transition age child SSI recipients.

Another possibility is to expand payment options for serving child SSI recipients. Presumably, most child SSI recipients would not be in a position to work full-time until they completed school. Consequently, payments for these services would need to be made based on achieving other outcomes, such as the completion of additional schooling, training or other employment-related activities. Currently, several welfare to work agencies are providing performance based incentives that account for non-employment outcomes in reaching “hard to serve” Temporary Assistance for Needy Families (TANF) populations (Kramer, et al. 2002). SSA could develop a reimbursement system that

reflected these diverse outcomes. For example, providers could be paid if a child SSI recipient met a specific training objective, such as the completion of a vocational course. Presumably, this type of option could be incorporated into an expanded Ticket program for child SSI recipients, such as that suggested earlier by the Panel.

The potential limitations of these options, however, are similar to those for expanding the Ticket program to transition age youth. Namely, a change in VR funding priorities could inadvertently create the impression that SSA is valuing work over other objectives, such as continued schooling. Further, payments for outcomes under these options could be complicated given that many youth might not be eligible for SSI after age 18.

Another concern is that access to other vocational preparation activities at the state level is generally limited, particularly at One-Stop Career Centers. Currently, One-stop Career Centers are the focal point of federal workforce investment strategy for adults under WIA, but are not mandated to serve youth under 18.¹⁴

One way to expand access to work preparation and training services for young people with disabilities is to lower the age range for mandatory service to age 16. This expansion would allow more students in special education and other young people with disabilities access to these services. Youth could use these centers to obtain more comprehensive assessments, individual employment plans, group and individual career counseling and case management, and short term pre-vocational services, occupational and on-the-job skills training.

One advantage of using one-stops to expand access to services for youth is that these centers are already mandated to serve persons with disabilities, through the requirement that they provide universal access to core services. This means One-stops already have to address the issues of physical accessibility, appropriate assistive technologies, employer accommodations, outreach to people with disabilities, and forming partnerships with disability groups in the community, including but not limited to VR. That said, while this option may be a promising avenue for expanding access to vocational services to youth, it is not yet a fully developed system for adults with disabilities. Findings from a recent survey suggest that while One-Stops are making progress in serving the disability community, in many areas adults with disabilities may not yet have access to the full complement of One-Stop services. (Storen et al. 2002).

Another aspect of One-Stops that could be expanded to better serve youth is the Disability Program Navigator project (SSA 2003). This two-year demonstration project, jointly funded by SSA and DoL, establishes specialists who serve as a resource to and advocate for people with disabilities who seek employment and training services in the One-Stop Centers. Navigators will link people with disabilities, including DI and SSI recipients, with employers and with benefit planning, assistance, and outreach organizations and they will have training regarding SSA employment support programs, work incentives, and Ticket to Work. As this project continues, lessons learned could be applied to a similar position focused on youth, located in One-Stops or in schools. SSA

¹⁴ They can serve youth ages 18 to 22 who are in or out of school

and DoL Social Security Administration and DOL are currently in discussions about creating navigators for youth with disabilities (Mazerski 2003).

Cost is a key issue for expanding the scope of One-stop Center services to youth with disabilities. We anticipate that these youth will utilize more expensive intensive services given their complicated needs. Already, in areas with limited funding, priority for these services is given to low-income adults and recipients of public assistance (Storen and Dixon 1999). Consequently, any expansion of coverage to younger age groups may also need to carry some restrictions on use of intensive services, given limited resources.

D. Coordination of Services

There is generally no explicit facilitator, planner, or coordinator focused exclusively on the transition process and the complex mix of programs available to child SSI recipients. The team writing the IEP serves this role for some special education children, but significant variation exists in the quality of the IEP and/or the knowledge of the writer (Beckett, Gracechild, Westrom 2003). With special education resources stretched thin, implementation of the plan by existing school personnel may not be happening without a key person to assist the youth and his/her parents in accessing the needed services. In addition, SSI recipients who do not receive special education services do not have an IEP so may have even greater problems navigating the transition process. Many families of SSI recipients are low-income. Some have low levels of education, are non-English speakers or recent immigrants that will have additional problems helping their children navigate the transition process. Finally, as evidenced in the YCDR demonstration, it is not clear that school personnel have (or should have) requisite knowledge about Social Security work incentive provisions and redetermination process to help youth and their family makes key decisions (Maximus 2002). Given the complexity of these rules and the reluctance of families to jeopardize benefit status, identifying facilitators with this knowledge is very important.

SSA could develop a role for a representative to participate in the IEP process. If the child SSI recipient is not enrolled in special education, this SSA representative could help fulfill the role of the IEP. In the YCDR demonstration, Maximus developed a model for transition planning, called the Youth Transition Planning process (YTP). The YTP can serve as an example for how dedicated transition staff can develop and implement transition plans for youth with disability in conjunction with schools, VR, and other community services. The staff in the field for this demonstration project served the role of planner and facilitator, with knowledge of school and community service options, able to leverage existing available resources. They also had expertise on SSA benefits and work incentive programs. The plans were individualized to the youth's specific needs and circumstances, without a "one size fits all" approach.

The transition planner role could be funded jointly through school systems and SSA. Potentially, actual staff could be dedicated school employees (or dedicated in part) or from contracted community-based organization personnel. Because collaboration and building relationships between the schools, VR, and other community service providers is

key, a model could be used from other organizations that have already developed some of these links.

As above, cost is a major concern in expanding developing this option. One particularly difficult barrier could be trying to prove that the benefits from this type of collaboration in the long-run outweigh the immediate costs of providing these services. Another concern is the possible conflict of interest that SSA might have in providing transitional services. For example, if the SSA representative is seen as a person primarily trying to find opportunities to move a child off SSI after age 18, some advocates might raise concerns whether this representative is in the best long-term interests of the child. Consequently, it is important that all involved parties, especially families of child SSI recipients, understand the role of the transition planner.

E. Educational Opportunities

The focus on high stakes testing and integrating students with disabilities into mainstream classrooms has created incentives for many local education agencies (LEAs) to cutback Vocational Education programs. Given the positive correlations between these programs and outcomes for special education students found in the previous literature, this cut back could have a negative effect on a child's options for obtaining specialized training. Further, the emphasis on high stakes testing could serve as a disincentive for some struggling with standardized testing to complete secondary school.

A related concern is the low enrollment rates in post-secondary education for youth with disabilities from special education programs. Unfortunately, detailed data on these outcomes do not exist for child SSI recipients, though the findings from the special education literature and anecdotal evidence from several experts suggest that child SSI recipients generally have relatively low enrollment rates in post secondary education.

It is important, but difficult, to develop specific options to address these concerns that are consistent with broader movements within the education system. For example, one possible option is to amend IDEA to include performance incentives that are directly tied to vocational education. Another possible option could be to include professional development training for faculty and administrators and the development of more accessible teaching methods, such as remote classrooms over the internet. However, these options, which promote access to more specialized programs and individual attention, could be seen at odds with current educational trends that emphasize the importance of high stakes in maximizing the performance of all children by setting high standards.

To better understand these issues, we suggest that SSA and DOE develop demonstration projects and databases. One option would be to develop demonstration projects that track the outcomes of different groups of youth across high stakes testing programs and other specialized programs in a variety of environments. Alternatively, SSA could develop demonstrations or special waivers that promote higher education as an important

outcome for recipients. The viability of this demonstration, however, is likely limited given the many child SSI recipients will not remain on SSI after age 18.

F. Expectations by Parents and Administrators

Unrealistically low expectations for a young person's ability to work can lead to lack of work preparation and limited options. People involved with a young person, including educators, other school professional and parents may not expect/believe that young person with a disability, especially a severe disability, can work. Anecdotal evidence suggests that the lack of expectation that a young person can ever make the transition to work or independence is a serious barrier in the transition process. Low expectations can be rooted in lack of information on options or of role models of successful transition. Real concerns over benefit loss, sustainability of work, and potential for independent support also play a role in youth's, families', or involved professionals' low expectations for work or skepticism about the potential for transitioning to independence.

Improving expectations and attitudes can be addressed through several mechanisms. First, parent and/or youth advocacy training can encourage parents and youths to advocate for their children or themselves. This type of training could include education on available options, exposure to success stories and role models of workers with disabilities, and training in tools that could help in navigating the complex set of transition programs. SSA could develop such a training program or fund existing training programs. This program could also involve concurrent training of teachers/parents to be coadvocates for students. This type of training may have the added benefit of reducing the sometimes adversarial feeling around IEPs that develops between parents and education professionals. Some federal funding already exists through Parent Training and Information Centers from the DOE. Independent groups such as DREDF (Disability Rights Education Defense Fund) also provide this type of training and curriculum development. SSA's involvement would allow for the additional component of adding information about work incentive provisions that could temper fears around benefit loss.

A potentially more effective mechanism for changing expectations is by having available real options for vocational preparation for competitive work and getting young people involved early. Participation in work or vocational activities can be a powerful way to change expectations. Anecdotal evidence suggests that greater inclusion of youth with disabilities in "mainstream" work preparation activities (such as summer jobs programs) can have benefits for work (Beckett, Gracechild, Westrom 2003). This also requires that the professionals involved in providing transition services and planning for youth are able to assess the potential of individual youth with disabilities and involve them (and their families) in appropriate goal setting. Given the problem of low expectations, youth may not on their own develop or advocate for long-term goals that they could potentially reach. Low expectations for work of school-based or other professionals can reinforce low expectations instead of helping to counter them in a realistic fashion.

While motivation and realistic goal setting are key components of successful transitions, concerns over the long-term ability for young people with disabilities to support themselves are also real. This suggests that attempts to address low expectations in

isolation may not be as successful as combining these activities with other policies that increase access to transition options and provide some safeguards on benefit loss.

G. Research

As noted in several areas above, the lack of research information on transition outcomes of youth with disabilities in general, and child SSI recipients in particular, makes it difficult to identify specific policy recommendations in serving this population. Unfortunately, relatively few data sources include information on youth with disabilities. While some progress is being made in this area, more information is needed to develop effective policies to serve this population. As noted in several concerns above, because of these current limitations, many questions about important aspects of the transition process remain unanswered.

Researchers should be able to use upcoming data sources from SSA and DOE to examine a variety of transition issues. The NSCF should provide options for researchers to better understand the transition process of child SSI recipients. These data, which should be publicly available in the summer of 2003, include information on demographic characteristics, disability status, health insurance and utilization, education and training, other programs and services, SSI experience, employment, assets, and other outcomes (e.g., imprisonment). The National Longitudinal Transition Survey 2 (NLTS2) is also collecting data on a large, nationally representative sample of students in special education aged 13 through 17 that will be important for research on transitions. Researchers could use this survey to examine emerging issues for secondary school aged youth in transition, including program overlaps across SSI and special education.

Despite these new resources, however, there is a need to develop a more focused research agenda through interagency collaboration. This collaboration could help define a more coherent research strategy in defining successful outcomes for transition age youth.

One promising option is to develop an interagency research center across key government agencies, especially SSA and DOE. The department would be in charge of fostering data collection activities and developing a research agenda to address emerging policy questions. The DOE already funds several Research and Rehabilitation Training Centers (RRTC) on a variety of disability related topics at major universities across the country. It might be possible to create an RRTC through DOE devoted solely to addressing issues related to the transition process of youth with disabilities. Alternatively, SSA could develop a center similar in concept to the current Disability Research Institute (DRI), that would focus specifically on child issues. The advantage of funding a research center through SSA is that it might be possible to make better use of SSA administrative data to track long-term outcomes of child SSI recipients. The drawback, however, is that an SSA center would focus on a narrower part of the population with disabilities (child SSI recipients) in comparison to a center from DOE, which would likely focus on the broader population of youth with disabilities in special education programs.

The advantage of developing a more focused research approach is that it could significantly enhance the quality of existing research and, potentially more importantly,

ensure that there are sufficient resources for future research efforts. For example, because the NSCF and NLTS2 are both one-time surveys, they will only include information on one cohort of youth with disabilities. Consequently, there will be a need for additional data sources to track outcomes for later cohorts of youth with disabilities, particularly as policy towards these recipients continue to unfold in future years.

Wittenburg, Golden, and Fishman (2001) recently identified two specific data initiatives that could be developed through a dedicated research center. The first initiative would be to improve the information on child disability status and SSI program status collected in major surveys. One example of such an effort would be to improve the existing information in national cross-sectional databases, such as the Survey of Income and Program Participation (SIPP) and Current Population Survey (CPS). Both of these aforementioned surveys provide detailed program participation information on a nationally representative sample and, hence could be used to examine multiple program participation patterns of youth. The second type of data initiative would be to develop administrative databases that can be linked to other databases to track transitions by youth with disabilities. Several states have promising administrative databases that track program participation across a variety of programs, including special education. The evolution of these databases could generate new possibilities to address research questions related to transitions on an on-going basis.

H. Summary

We summarize the major concerns and individual policy options from above in *Table 1*. Our summary is organized according to our several general concern areas (Work Incentives, Provider Incentives, Access to Vocational/Work Preparation Services, Coordination of Services, Expectations for Youth with Disabilities by Parents and Administrators, Educational Opportunities, and Existing State of Research Knowledge). This summary illustrates concerns that arise due to the complex nature of the transition process, as well as the myriad of policy options that exist in working with various government agencies to improve policy for transition age youth.

Table 1: Summary of Concerns and Options

Concerns	Options
Work Incentives	
The SSI program includes several disincentives that discourage work and even participation in work preparation activities for many child SSI recipients. These disincentives are likely further complicated by the age 18 redetermination decision.	<ul style="list-style-type: none"> • Expand the use of PASS and IRWEs for child SSI recipients. • Remove the earnings cap covered under the SEIE. • Exclude all child earned income in the calculation of SSI benefits.
Child SSI recipients do not have access to a temporary source of cash benefits (or other supports).	<ul style="list-style-type: none"> • Extend eligibility for benefits beyond age 18. • Create a temporary disability program for some segment of child SSI recipients.
The potential loss of Medicaid benefits is a strong work disincentive even for those with limited earnings.	<ul style="list-style-type: none"> • Provide Medicaid waivers to be consistent with SSI work incentives programs. • Transitional Medicaid assistance could be guaranteed for former child SSI recipients for some set period.
Provider Incentives	
There is a general need to improve individual incentives for self-sufficiency in non-SSA delivery programs.	<ul style="list-style-type: none"> • Tie funding for programs to individual outcomes • Develop interagency collaboration to set objectives across programs (e.g., agencies could develop joint waivers that empower consumer choice and more sharply tie incentives for providers to client outcomes within specific programs, as well as across programs).
Vocational/Work Preparation Services	
Vocational Rehabilitation is the foremost public avenue for work services for people with disabilities, but access for many youth is very limited.	<ul style="list-style-type: none"> • Make youth a priority group for VR agencies. • Expand payment options for serving child SSI recipients.
Access to other vocational preparation activities at the state level is generally limited, particularly at One-Stop Career Centers.	<ul style="list-style-type: none"> • Lower the age range for mandatory service at One-Stops to age 16. • Expand the Disability Program Navigator.

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Coordination of Services	
There is generally no explicit facilitator, planner, or coordinator focused exclusively on the transition process and the complex mix of programs available to child SSI recipients.	<ul style="list-style-type: none">SSA could develop a role for a representative to participate in the IEP process.
Educational Opportunities	
The focus on high stakes testing and integrating students with disabilities into mainstream classrooms has created incentives for many local education agencies (LEAs) to cutback Vocational Education programs.	<ul style="list-style-type: none">SSA and DOE could develop demonstration projects and databases to better understand these issues.SSA and DOE could design options together that are consistent with broader trends in the educational system.
Enrollment rates in post-secondary education for youth with disabilities from special education programs are low.	
Expectations by Parents and Administrators	
Unrealistically low expectations for a young person’s ability to work can lead to lack of work preparation and limited options.	<ul style="list-style-type: none">Parent and/or youth advocacy training can encourage parents and youths to advocate for their children or themselves.Expand options for vocational preparation for competitive work
Research	
The lack of research information on transition outcomes of youth with disabilities in general, and child SSI recipients in particular, makes it difficult to identify specific policy directions in serving this population.	<ul style="list-style-type: none">Researchers should be able to use upcoming data sources from SSA and DOE to examine a variety of transition issues.Develop an interagency research center across key government agencies, especially SSA and DOE.

V. CONCLUSION

Our findings suggest a number of potential areas of concern related to the transition process of child SSI recipients. We identify several specific concerns related to this process, including a number of work disincentives associated with SSI and Medicaid; possible conflicts between provider and individual incentives; obstacles in accessing work preparation services; a lack of coordination of services across agencies; low expectations for youth with disabilities by parents and administrators; a potential lack of access educational opportunities; and limited research information on transitions.

Because of the diversity within the child SSI population and the complexity of the transition process, there is no “one size fits all” option that would universally improve this transition for all child recipients. Rather, we identify several policy options to address multiple concerns.

However, our ability to make specific policy recommendations is hampered by the lack of information on the current transition processes of child SSI recipients. While we suggest an option to develop a more coordinated approach to address this major concern, the ability for policy makers to assess the benefits and costs of many of the proposed options is generally very limited given the current state of knowledge regarding these transitions. Nonetheless, the concerns and policy options identified here represent an important starting point in considering new research and policy agendas for this population.

In assessing specific options and concerns, it is important to balance the overall objectives of the SSI program before making decisions on specific policy directions. In some cases, the options outlined above may change the purpose of the child SSI program. For example, the temporary disability option is a fundamental departure from the SSI program, which is intended to provide permanent disability cash benefits. Alternatively, it is important to balance options that are possible within the context of the current SSI program, such as balancing the need to improve work incentives with the objectives of providing cash assistance to low-income children with serious disabilities. Indeed, if policies to reduce work incentives for this group were implemented, there could be a political backlash if a large number of SSI youth, who initially became eligible because of severe disability, started entering employment.

Because of these issues, the SSA Ticket Advisory Panel will need to make important decisions about whether specific options could be incorporated into the existing child SSI program, or if substantial rethinking of the program is necessary to improve outcomes of youth with disabilities. It is possible that substantial rethinking might be necessary to improve the efficiency and equity of the current program for youth with disabilities, as well as for taxpayers.

The Ticket Advisory Panel should also consider these major concerns and options in light of upcoming legislative initiatives. While there are no major proposed legislative changes to the SSI program on the table, important reauthorizations are on the table for WIA and IDEA. Some of the policy options proposed here, especially those that fall

under our general areas of concern related to vocational/work preparation services, coordination of services, and education opportunities, could have some relevance to those reauthorization decisions. Additionally, while not necessarily part of specific proposal package, we suggest several different types of demonstration projects that could be implemented independent of a major policy initiative.

Another possible avenue for considering the concerns and options presented above is in special demonstration projects funded through SSA and other agencies. SSA has a history of tested various initiatives for both youths and adults, as evidenced in their current YCDR in Maryland and Florida. More broadly, SSA has also recently collaborated on several initiatives for adults disability recipients through the State Partnership Initiative (SPI) project (Agodini, et al. 2002). For the SPI project, SSA funded 12 projects through cooperative agreements and the Rehabilitation Services Administration (RSA) funded 6 projects as system change grants. In addition, the SPI projects received supplementary funding and support through the Department of Labor, the Substance Abuse and Mental Health Services Administration (SAMHSA) and several state agencies. Presumably, similar agreements could be structured to support some of the options noted in this paper, including those that required interagency collaborations.

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